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ABSTRACT

This booklet presents ideas and experiences of members of People First of Tennessee, including those with disabilities, an organization that is working to improve the lives of people with disabilities who still live in institutions. Emphasis is on their role as "next friends," people who get the attention of a federal judge regarding their needs when they cannot speak for themselves and have no family willing or able to do so. Individual items in the booklet cover: a meeting with a resident despite staff objections; ways to befriend people in institutions; the importance of eye-to-eye contact; communication with people who can't talk; ways to relate to individuals who act violent; the role of People First meetings; negative aspects of institution life; ways the institution may try to prevent People First members from befriending residents; and ways to deal with uncooperative institutional staff. (DB)

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Contributors

Rocky Akins
Ruthie-Marie Beckwith
Leanne Boyce
Bill Gage
Sam Gage
Bill Goodman
Crystal Goodman
Charles Hall
Frances Hamblen
Betty Henderson
Patricia Hornick
Jane Humphrey
John Kennington
Emily McFall
Matt McFall
Melinda McFall
Randy McFall
Hugh McLeary
Rex Stephens
James Turner

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This book is dedicated to the memory of
Emily McFall
a wife, mother, co-worker,
fellow member, and friend to all

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A Good Friday Visit

It was Good Friday at the institution. Afternoon cartoons were blaring from the television in the "living room" of one of the cottages where I sat observing Deborah, one of our People First members. Four staff members watched me sullenly as they sat in chairs along the wall. I had positioned myself across the room from Deborah after re-entering the building following a dispute over whether I could visit her.

For five years, Deborah's sister (her legal guardian) had opposed any contact between her and People First. This time, armed with a federal court decision, I had been determined to visit. When I first arrived, Deborah and I moved into the dining room to talk. I wrote questions on a tablet because she has trouble hearing. I asked her how she liked her job at the workshop in town. She started telling me about problems with her paycheck and described the type of contract work she did.

Less than five minutes into this quiet exchange we were interrupted by three staff members in quick succession, each challenging my visit. With each challenge, I explained the court's decision. After the third challenge I was invited to see the Supervisor who was anxiously packing up to go home, it being a state holiday and all. The Supervisor in turn had me talk on the phone to the Administrator on Duty who, realizing the legitimacy of my request, passed approval back down the chain of command.

However, by the time we had resolved the dispute, Deborah had also gotten the "message" and had withdrawn back into herself. So, on Good Friday I watched as she sat in her wheelchair talking to a small Teddy bear she clutched in her hand. "Don't worry, Cassandra," Deborah said to the bear, "I'll make sure you got some Easter Eggs. We'll look for some in the parking lot. There might be some in the parking lot. Don't worry....".

I wrote Deborah another note as I prepared to leave. I thanked her for taking time to talk to me and wished her a Happy Easter. She took the note and read it. She shook her head slowly and then set it gently on the table beside her. Not knowing anything else I could do, I picked up my back pack and headed out to meet my ride.

I walked across the grounds in the brisk spring air filled with anger and frustration. Three years after a major court ruling against the institution, little had changed. I visited six people that day, all of whom were still living out their lives on an island of isolation and hopelessness.

Fighting for Freedom is Hard Work

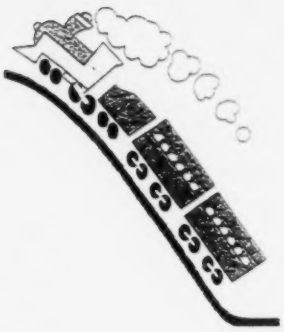
People First of Tennessee has worked hard to make some big changes for people who now have to live in institutions. Because they fought in court for institutionalized people, the State has agreed that people who now have to live in four institutions will get the services they need to move into their communities.

One way that People First members helped to win this victory was by acting as what lawyers "next friends" for People First members who live in institutions. A "next friend" is somebody who gets a US Federal Judge's attention for people who need the Judge to protect their rights but cannot speak for themselves and have no family willing or able to speak up for them.

On December 14, 1996 People First Members and advisors met at the state People First Office to talk about what they had learned about reaching out and being friends to people who still live in institutions. They did this for three reasons...

- Because they want to continue to support people as they move out of institutions
- So that other members of Tennessee People First who want to be friends for people in institutions can learn from them
- So that members of self-advocacy organizations in other states who are working to close institutions can learn from them

The ideas and experiences in this booklet are in people's own words. John O'Brien from Atlanta, GA, listened to the meeting and kept notes on big charts. He checked his notes by reading them back to make sure that he got what people said. He organized people's ideas into this booklet. Then People First members and advisors checked the booklet, made corrections, and added more ideas and stories.



Clover Bottom Freedom Train Song

Get on board the freedom train is what I want to do
tell this institution that my days here are through,
find a home and get a job in the Community–
don't you think there's room enough for you and me?

Many years have come and gone since I've been in this place
waiting for an opening to join the human race,
three square meals are not enough to feed my lonely soul–
won't you give me one more chance to be made whole?

The days go by, each one's the same, no end to it in sight,
I try to keep my dignity and go on with the fight
to gain my liberation from this cold and heartless State–
can't you tell it's getting hard for me to wait?

I hear about the outside world and its opportunities,
I hear the whistle blowing for others just like me–
it's my turn now to get on board–I'm never looking back,
that freedom train is rolling down the track,

Get on board that Clover Bottom Freedom Train!
Get on board that Clover Bottom Freedom Train!

–Ruthie-Marie Beckwith
December 22, 1995

People who live in institutions need friends

People who live in institutions and people who are moving out of institutions need someone who will...

listen carefully to find out...

their hopes and what they want to get out of life
their concerns, worries, and troubles
what help they know they need

talk with them about....

their rights and how People First can help them get respect for their rights
what the Judge says has to happen when they move out of the institution
the ways other people with disabilities are living with dignity in their communities

help out with problem solving by...

sharing experiences and information and asking questions
encouraging them to keep working on important things, one day at a time

support them...

when their plans for moving out of the institution are made so that the plans make sense for them

advocate by...

keeping an eye out to be sure that people...

stay safe

get enough good food to eat
get good health care
have chances to make choices, go places,
and try new things
get good help with their problems
are treated respectfully by staff people

speaking up when things are not right and
their voice isn't heard

getting help from People First when the institution
doesn't do what's right

helping them to tell the Judge when the institution
won't follow the Judge's order

In one word, people need...

friends

who will be there for them so they know that they are...

not alone
not crazy to hope for better things
not bad to speak up for their rights and
work for what they want from life

Friends who will show them there are people in the community who...

will be on their side
have been in their shoes and are making their lives better
will be friends after they move out
want to help solve real problems
need them to join in to make changes so that
everybody's rights are respected

"Staff people sometimes like to control people, to sort of keep them in a box. With friends to help you can have the courage to stand right up out of that box and be yourself."

It begins with eye-to-eye contact

You look right at the person,

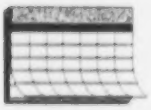
shake their hand,
tell them your name, and
ask them their name and what is on their mind.

Then you listen, and when it seems right, you tell them you want to...

be their friend
help them out
work to make sure their rights are respected
connect them to People First

Ask if there is anything they would like to help them with.

Before you leave...



ask the person if they will see you again
set a time and place to meet again

maybe at the next People First meeting, or
maybe where the person lives or works.

"I hadn't met her before she came to a People First meeting. She just needed somebody to help her out and I decided it would be me."

Some people don't talk...

even with signs or a communication board, but they still need a friend.

Some things to think about when a person doesn't talk...

eye-to-eye contact is important, the person needs to know you care about who they are

just because someone can't talk doesn't mean they can't understand,

talk to people even if they don't use words to answer you

it just takes time to get to know someone who doesn't talk; don't give up

ask other people what they know about how the person communicates, but don't give up if a staff person says, "That person doesn't communicate at all."

the more you are around the person, the better you will understand

some people tell you things with their eyes, or with the way they move their hands, or their bodies

some people tell you things with sounds, and sometimes, once you get used to them, you find out that the person is using words

it is good to ask staff people what they are doing to help the person communicate better; lots of people could use help with communication but haven't gotten it

of course, if the person uses a communication board, or signs, or symbols, or a picture book, or Morse code you either need to learn the person's way to communicate or have somebody be an interpreter for you

People who don't talk really need friends who will keep an eye on how things are going for them...

when they are sick it is very important to make sure they get good medical care

when they can't move around much on their own it's important that staff make sure they get places and have interesting things to do where ever they are

you can learn a lot by asking staff about how its going for the person; if they don't seem to know much or aren't very interested in the person, the person is in a bad spot

it's a good idea to talk to people who know a lot about how to help people who don't talk or move around much on their own, check with the People First office for names of people to talk to

Some people act violent

or yell or hit or break rules, but they still need a friend

Some things to think about...

People don't lose their rights because they break rules or even if they act violent

Even if someone is violent, it is not right for staff to hurt the person back, or be disrespectful, or take important things away from them, or keep them from seeing or calling their friends. (People First is still working to be sure there are clear rules for staff about this. If you have a friend whose rights are taken away for breaking rules or being violent, help out with what People First is doing about it.)

You don't have to agree with what somebody does to be their friend when they are in trouble. You just have to be there for the person and keep an eye out to make sure that staff respect their rights.

You don't have to know the right answer to keep the person from getting in trouble. You just have to be there for the person and be whatever help you can.

There are lots of ways to help people who yell or hurt themselves. It's a good idea to talk to somebody outside the institution or program who knows about these ways to help.

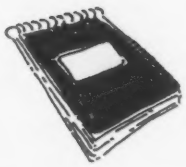
"I know him a long time before he got sent away. People were upset with him and staff weren't treating him right. He didn't have no other friends, so I asked if I could be his friend and he said yes."

People First Meetings are a very good place to start

and keep up a friendship.

Meetings give people who live in institutions a chance to be part of the People First team.

People can meet other members who have...
moved out of institutions
learned what their rights are and how to speak up for themselves



People can get information, support, and help from the whole Chapter.

The meetings are a good place to find out what is happening and to talk things over.

Sometimes it is easier for a group of members to get transportation from the institution to a meeting than it is for friends to get to the institution.

Many people still need someone to reach out to make friends with them. Make sure that someone makes one-to-one contact with the new people who come to a meeting.

It's very important to keep visiting institutions and inviting people to come to meetings.

The harder the institution tries to keep people from finding out about People First, the more important it is to keep trying to reach them.

The harder the institution tries to keep people from coming to meetings, the more important it is to work to get them there.

When people who have attended meetings don't come back, call or visit to find out what can be done to bring them back.

Some people may not want to come to meetings until they have a friend to help them get there and feel welcome.

"One of my friends is older and her speech is hard to get. But when she came to a meeting I caught her eye and she smiled and I knew we would be friends."

Together

Once we have made a friend, we can...

just sit and talk
go out together
help the person feel better when bad things happen
encourage the person to keep working for what they want

help staff and other people find out what a person is really like when...

the records are full of bad things about them

staff are saying they just can't do something
they are having a hard time

help our friend become a People First officer

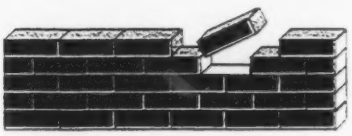
work together to help People First make changes in the way people with disabilities are treated

make sure that staff and the state administration stay with the laws and the agreements the Judge has approved

keep up contact and visit unannounced sometimes to make sure that our friend is all right

"Once I met her, and she knew I was her friend, I made sure to leave it to her to reach out, so that she knows she can do it for herself. When she comes to me, I listen. The more she talks, the more I listen. Now she is out of her shell and going like a rocket."

Institutions put walls between friends



Institutions try to keep us away from each other by keeping the doors closed between us.

The institution has...

kept us from coming in to visit a friend

told us we have to leave and have no right to be there

made our friends disappear by moving them and telling us that they will not say where our friend has moved because of confidentiality

kept a person who wants to come from attending People First meetings because she has been moved from a building where staff take people out to a building where staff don't take people out (The people in the second building are older. In that institution, people lose the right to go out just because they have more birthdays.)

refused to let people out to come to People First meetings

kept people from getting mail about People First

kept people from making or getting phone calls between friends

Sometimes the institution even separates people inside the institution who are friends from each other.

Many people have lost contact with their families because the institution makes it hard for them to stay in touch.

When we do get to be with people, the institution still tries to be in control...

they try to tell us when we can see our friends and for how long (even during free time)

they try to tell us where we can see our friends

they say they have to be present because if they are not we will confuse, or upset, or manipulate our friends

"Nobody says this right out loud, but what I hear behind the way staff act is that they really believe I could never be somebody's friend or be any help to them because I have a disability too."

Staff who bring people to People First meetings sometimes try to keep the wall around the people right at the meeting by...

making all the people they brought sit together with them

telling people not to talk to other members

listening in when people try to have a private conversation

interrupting people when they talk

Some people who live at the institution say, "No, we don't want friends from People First." We think this is because...

the institution is the only security they know and they don't have information about living in the community so they think we want them to go out without the help they need and get hurt

the institution, and sometimes their own families, tell them that People First are bad people who want to hurt them

they are afraid that if they go against what the institution wants, staff will make them pay for it (Many people have been punished or even physically abused by staff for disobeying or speaking out, and just about everybody has seen someone else get hurt just for crossing staff.)

One of the best ways the institution has of trying to control people is to just ignore them. Some of us have made call after call to set ways for our friends to join People First meetings.

The institution just doesn't call back. If they do call back, they say they can't do anything now but they'll call back later and then they don't call back later. If they do agree to do something, they just don't do it and then don't call back when you want to ask why they didn't do what they said they would.

Another way the institution controls people is to lie about what happens to people. A People First member got bruises from the way staff handled her; other members saw the bruises and heard how it happened. But the staff said it didn't happen. All the way up the line supervisors said it didn't happen.

We have even heard staff people lie about things we know happened when they are under oath to tell the truth. When the institution won't even admit that there is a problem, it is very hard to work on a solution.

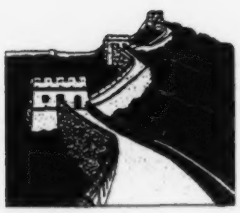
Mostly, the people who keep the walls up stay pretty cool and act like they are just doing their job. But sometimes the wallkeepers get really angry at us right out loud and say things like...

"How dare you interfere! This is none of your business!"

"You don't know what I have been through and how much hurt you are causing me!"

"You are ignorant! You just don't know anything."

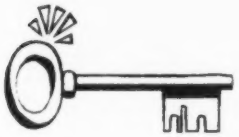
"Get out of here!"



Often it is people's family members who say things like this to us. We think this is because the institution wants to turn people who care about the people inside the walls against each other. We don't want to hurt anybody, we just want to be sure that people get what they deserve.

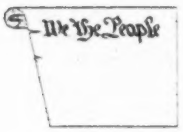
"It makes my heart hurt to hear people say and do ugly things like this because it means to me that they don't recognize that the people in institutions are just humans."

What we can do to get through the walls



When the institution tries to separate us from our friends we can...

Be firm, but not hateful back at the staff people in the way



Tell the staff people in the way that it is right for people to have friends and belong to People First if they want to

Ask the staff people in the way to step aside so we can see and join with our friends

Make it clear that we have no intention to upset or confuse people, we just want to see our friends, and get to know them, do things with them, and make sure their rights are respected

Sometimes a staff person just will not let us see our friends and will not be moved. It's good idea to let the People First office know about this. It may be something that can be settled with the institution. It may even be something that will need to be settled by the Judge.

Sometimes a People First staff person can be a go-between to set up contacts with a friend.

Being kept from seeing a friend can make you made. It's right to be angry, but it's important to stay cool and not lose your temper. If you lose your temper bad, the institution might use it as an excuse to keep you out.

The way the institution treats you can make you scared. Remember...

You have the support of People First

You aren't in the institution any more; it might keep you away from your friend, but it can't get at you.

If the institution scares you, think what it can do to our friends inside if we give up and go away.

Even if the institution makes somebody disappear and we can't find them or get to see them, we can be sure that we never, never forget them.

"The institution won't give up easy. It's not just those four big places, those walls can come up anywhere. We have to keep working to tear down those walls."

Why are the walls so strong?

It is good to know what makes the institution strong. When we know what makes the institution strong, we can do a better job of tearing them down.

The walls are strong because...

Lots of people think that people with disabilities can't do anything and will get hurt or in trouble if the institution does not control them.

Lots of people don't believe that people with disabilities have the same rights as anybody else. Sometimes even people on committees that are supposed to protect people's rights think that it is fair to keep a person from talking to their friends or going to a People first meeting just because they talk back to a staff person.

People in charge of the system don't want to take responsibility for making the kinds of big changes that it will take to make the kind of community services that respect people's rights.

Some staff people are scared because their wages and their careers are all tied up with the institution. They think if people leave the institution there will be no more work for them and so they want people to be scared of People First so they will not want to leave.

Some family members (and some staff people) just don't believe that there is any place but the institution that people can get the help they need.

Some people who think this way are afraid that they would seem like bad people if they admitted that something better could happen for the person they care about.

Many of the services in the communities have been weak and have sent people back to the institution instead of figuring out how to help them better.

If people leave the institution for good, they will have to get much better at their jobs.

"I think the institution people are scared because so many bad things have happened to people in there that they would make a pile as high as the moon if they ever came out. I think that people are scared to face up to what the institution has done because if they do, they have to face up to their own part in it."

Everybody needs friends

who will work together

to tear down the walls